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LEEDS BECKETT UNIVERSITY

AN INDEPENDENT EVALUATION OF 'DEMENTIA DIARIES'

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1. Background

Dementia Diaries is a programme that seeks to develop a public record and a personal archive of individuals' experiences of living with dementia. The project uses 3D printed mobile handsets to enable Dementia Diarists to audio record people's diverse experiences of living with dementia (On Our Radar, 2015). These audio entries are accessible via the Dementia Diaries website with the intention of 'amplifying' the voices of individuals experiencing dementia via the media.

In November 2015, Leeds Beckett University were commissioned by On Our Radar to undertake an evaluation of Dementia Diaries. The evaluation had the following primary objectives:

- i. To assess the extent to which Dementia Diaries has influenced media coverage and key services which affect the lives of people with dementia.
- ii. To ascertain the value placed on Dementia Diaries by those who are engaged with the project.
- iii. To determine the perceived impact and influence of Dementia Diaries by those who are engaged with the project.

This report highlights outcomes and learning from Dementia Diaries, focussing particularly on the participants' experience of being engaged in the programme. In addition, the views of those stakeholders engaged directly in the delivery of Dementia Diaries is ascertained as is an assessment of the overall impact the project has had on the media portrayal of dementia.

2. Gathering Evidence

A multi-pronged approach to gain a 360-degree view of the Dementia Diaries project was deployed within the evaluation. To do this, it was necessary to ascertain the views of the various stakeholders in contact with the service. Such 'triangulation' of data relied on collecting evidence of impact from a variety of different sources and making conclusions based on the overall data collected (Torrance, 2012).

There were several strands of evaluative activity. The first was ascertaining the views of the Dementia Diaries programme team to establish the project's Theory of Change. This is presented in the following section. The advantage of using a Theory of Change approach is that it helps make explicit the links between activities delivered (i.e. producing audio diaries) and programme goals (i.e. awareness raising and influencing media coverage).

The next strand, presented in section 4, involved eliciting participants' views and the views of their families about Dementia Diaries. To do this, we initially invited all project participants to submit an audio entry using the project's mobile connectivity solution – we requested individuals to respond to the following: 'How has the Dementia Diaries project affected you and what would you like it to achieve in the future?' From this, a further 16 in-depth interviews were undertaken (11 individuals living with dementia and 5 family members) with those who wished to provide additional information on the project. The focus of these interviews was to illuminate individual journeys and to explore the pathways to engagement and how experiences of the project link to impacts and outcomes. Finally, utilising the existing data gathered by 'On Our Radar', we analysed the media outputs generated from Dementia Diaries and compared the content of Dementia Diaries articles and social media content with comparator articles to see what, if any, differences there were in social media response.

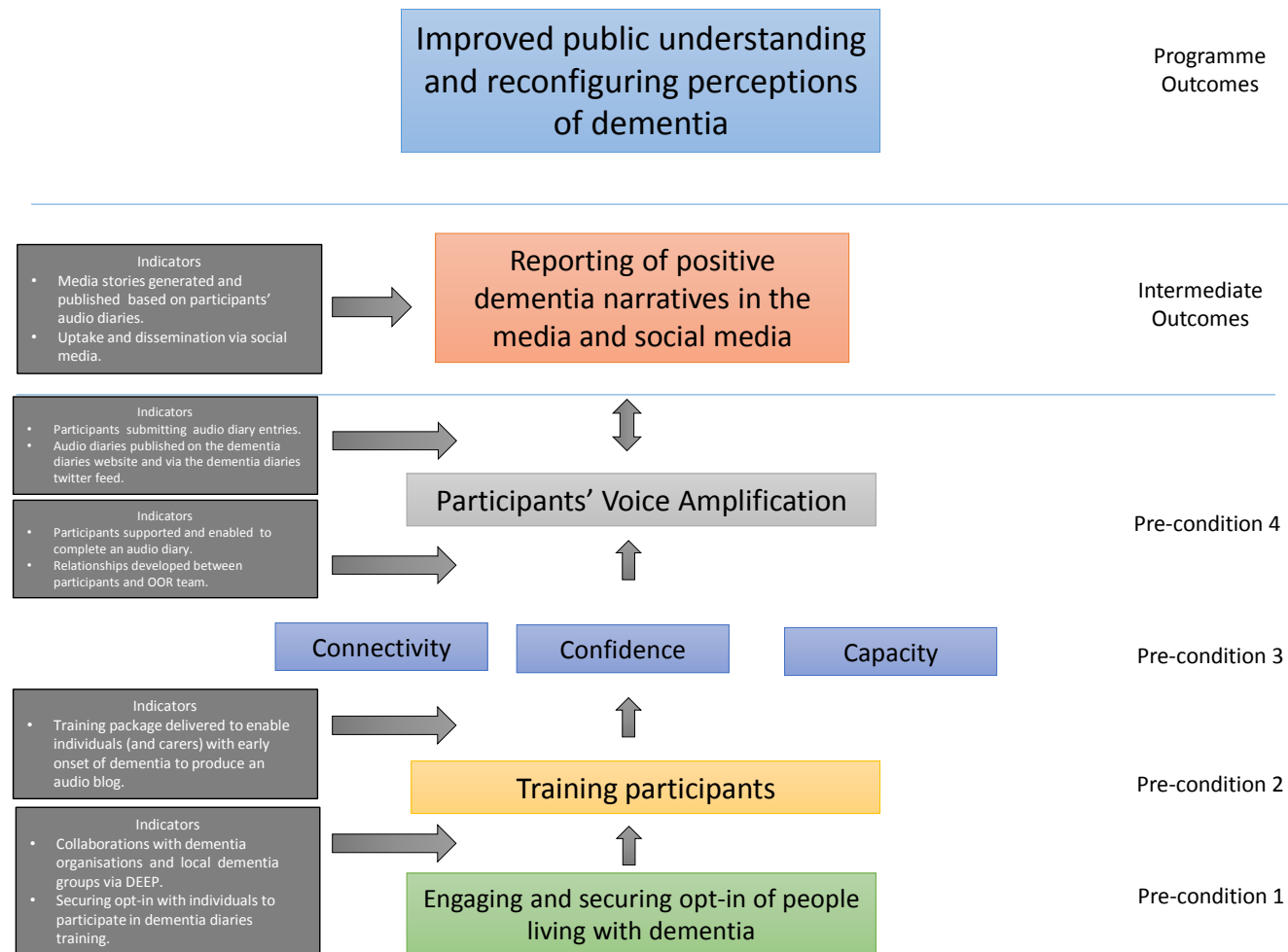
3. Developing Dementia Diaries' Theory of Change

Theory of Change is an approach, not necessarily a prescribed methodology (Green and Tones, 2010), but since its original inception Theory of Change has been a popular approach for evaluating complex social programmes which often involve interventions with multiple components leading to multi-level outcomes. The Theory of Change provides a means of unpicking the steps along the pathways of change – or indeed the complex networks. It involves ‘surfacing’ the latent theory which outlines stakeholders’ expectations about the various steps along the pathway linking activities to the achievement of goals. This is done through a facilitated process which draws on existing knowledge and theory and also the insight of practitioners and other stakeholders. Evaluators and stakeholders work together to ‘co-construct’ the theory of change for an initiative (Green and Tones, 2010). The process of creating and critiquing a Theory of Change encourages delivery partners to be explicit about how resources will be used to bring about the preconditions of the long-term programme goals. The advantage of using a Theory of Change approach is that it helps partners and stakeholders make explicit the links between activities delivered and programme goals.

All members of the Dementia Diaries team were brought together to develop and agree their ‘theories of change’ – this was a process of co-construction between evaluator and practitioner (Green and South, 2006). The following stages to develop the Theory of Change were:

- a) Identification of long-term goals and the assumptions behind them.
- b) Backwards mapping to connect to the preconditions or requirements needed to achieve the goal.
- c) Identification of the actions undertaken to achieve the desired change.
- d) Developing indicators to measure outcomes to assess the performance of the initiative.
- e) Writing a narrative explaining the logic of the initiative.

Facilitated by a member of the evaluation team, a discussion and ‘map’ was designed of the preconditions required to bring about the long-term goal of the programme. This is presented on the following page.



Testing the Theory of Change

The role of evaluators is not only to co-create the Theory of Change alongside delivery partners, but to ‘test’ whether the proposed programme logic does lead to long-term outcomes. A proposed overview of how the logic will be tested is presented below in table 1.

Table 1. ***‘Testing’ the Theory of Change***

Step	Assumption	Indicators of achievement	Status
Step 1: Engaging and securing opt-in of people living with dementia	In order for the dementia diaries project to be successful, individuals with early onset of dementia need to be recruited.	Collaborations with dementia organisations and local dementia groups via DEEP. Securing opt-in with individuals to participate in dementia diaries training.	<u><i>Achieved</i></u> The dementia diaries team have successfully engaged and ascertained consent from individuals with early onset of dementia to take part in audio blogging. Facilitated through DEEP and other local dementia groups, there are 44 (out of 55) individuals who are actively involved and engaged.
Step 2: Training participants	Appropriate training in how to use the mobile device and to audio blog is necessary for participants (and carers) to engage with the project.	Training package delivered to enable individuals (and carers) with early onset of dementia to produce an audio blog.	<u><i>Achieved</i></u> Training has been conducted across several UK locations (see following section presenting qualitative data from participants and their family).

Step 3: Connectivity, capacity and confidence	As well as technical understanding in using the mobile device (connectivity), developing the capacity and confidence of individuals to submit an audio blog is deemed essential.	Participants supported and enabled to complete an audio diary. Relationships developed between participants and OOR team.	<u>Achieved</u> Regular contact is made with participants to build confidence, report on progress and to offer feedback on audio content (see following section presenting qualitative data from participants and their family).
Step 4: Participants' voice amplification	Individuals produce and submit an audio diary for publishing on the dementia diaries website.	Participants submitting audio diary entries. Audio diaries published on the dementia diaries website and via the dementia diaries twitter feed.	<u>Achieved</u> There have been 1965 audio diaries submitted and 526 have been published on the dementia diaries website (also see following section presenting qualitative data from participants and their family).
Step 5: Improved public understanding and reconfiguring perceptions of dementia	Publishing dementia diaries will reconfigure and improve understanding of the condition.	Circulation of stories on media outlets and social media.	<u>Achieved</u> There have been a number of high-profile media stories that may be contributing to changing views of dementia (see section on media analysis and impact), with more than 60 cases where the content has been used to engage media, service providers, or researchers.

Evaluation is central to practice and is an essential activity that should be integrated in a programme from the outset. While various evaluation frameworks exist, the Theory of Change offers a viable way of mapping and articulating clearly the implicit assumptions embedded in a complex community programme. Moreover, as well as being an evaluative tool, the Theory of Change approach can be useful for sharpening the planning and implementation of an intervention (Green and South, 2006).

This section has reported key findings from a workshop conducted with members of the Dementia Diaries team. From that discussion, a Theory of Change as to how longer-term outcomes would be achieved were proposed which offered an evaluation strategy and framework. The next sections seek to verify assumptions and programme logic through eliciting views of the Dementia Diaries participants and their families.

4.

5. Findings from Dementia Diaries Participants and their Families

This section brings together salient themes that emerged from participants submitting individual audio blogs to the question ‘How has the Dementia Diaries project affected you and what would you like it to achieve in the future?’ and through individual interviews with diarists and their families (mainly spouses) who volunteered to provide further information in addition to their audio blog. Illustrative quotations have been used to highlight key thematic areas and where this has been done they have been anonymised.

Diarists’ journey

The notion of a ‘journey’ towards becoming fully involved and engaged in Dementia Diaries was reported by respondents. The journey for all participants encompassed their original motivations for getting involved and the process of training to understand how the systems, technology and processes ‘worked’.

Primary motives

The analysis of the data showed two core motives for participating in the Dementia Diaries project. The first motive could be broadly conceptualised as altruism – a sense of supporting other people experiencing dementia and services associated with the condition.

Overwhelmingly, most diarists joined the project because they wanted to help to create more awareness and promote understanding of dementia whilst helping people diagnosed with dementia:

“My motivation was to get dementia out there and to make things easier for people with dementia coming behind me.” (DD2)

“[Name of participant] and I both wanted to as involved as possible with anything that would promote I guess the understanding or the acceptance of dementia.” (DD11 – family member)

Some participants’ motivation was not only to raise awareness with individuals experiencing similar situations to themselves, but for this awareness raising to penetrate political decision-makers (both locally and nationally) and those involved in the media portrayal of ‘living with dementia:

“It was to help people because I think they [On Our Radar] are going to feed that back then to the government to let the government know the views of people living with dementia and their carers.” (DD16 – family member)

“I think partly the fact that there was a sense of usefulness attached to it by the way of the contributions. Both to other people with dementia and to the media. One hopes that what you place on the site is listened to and read by other people with dementia. It might help them. But I know that the media do use it. Linked to that I think it has a usefulness in raising awareness generally around dementia which motivates me to be involved.”

(DD9)

The second key motive for joining Dementia Diaries was social connectedness and to bring together the dementia community. Reducing isolation and sharing ideas and information was seen as a key motivator:

“We felt it would bring the dementia community together because when they were telling us they said that other communities, people living with dementia would be a part of it and because it’s such a diverse community even though we’ve all got dementia we’re all very different obviously. So it’s a way of bringing us together, that’s what we thought at the time and that has certainly been the outcome of it.” (DD1)

“I think my motivation was I was feeling quite isolated [...] I just felt it was a way of connecting and maybe finding out are we going through the same symptoms, are we dealing with it, could I get tips from them, and it just appealed to me in a bizarre sort of way.” (DD7)

Training

The training process to enable diarists to understand the technology and purpose of the audio blogs they would create was received, almost universally, positively. The pace and delivery content was praised and where individuals encountered difficulties, bespoke solutions were provided. For example, a spouse of a diarist explained that initially the training was difficult for her husband to grasp but the team were able to adapt the training and slow it down and offer one-to-one support:

“The practicality of actually using the recording equipment was too much for [name], so we sort of got a bit behind at that point and came a bit unstuck. But they took us both out of the room and we sat somewhere else and went through it very slowly and carefully, with me helping [name] how to use the device.” (DD12)

Initial concerns about the technology and understanding how it worked were quickly allayed. Most diarists emphasised that the technology is simple in design and extremely easy to use. They described a process by which they press a button and are able to record their entries which are automatically uploaded and then eventually transcribed. Training content allowed

time for individuals to familiarise themselves with the technology and to get hands-on. Many suggested that the simplicity of recording an entry is a key feature of the project.

"I think it's so simple. It's simplicity at its best. It's just one press of a button and you are there. I can't think of anything simpler, you know record. If I was to forget what it was like I'd just see record and I'd know I needed to press that button." (DD12)

Where individuals did find difficulties, again tailored solutions were offered:

"So the challenges I had was it was hard to use the phone because it didn't look like a phone and I kept losing it, so the outcome was that Laurence gave me a number that I can use on my own phone and do my reporting that was. That was a problem and then a resolution was found and I liked that." (DD7)

"So very quickly it became apparent that either by phone or by text or by email was the way that it was going to work better for me." (DD9)

Support from the Dementia Diaries team: the "key to this thing working"

All of the diarists and their partners praised the project staff for their commitment and dedication to the project. The level of support and encouragement given by the staff, particularly Laurence, was a resounding theme throughout the data:

"It's run really well. We get updates about how it's going. I speak to Laurence regularly as to how I'm doing. He's a great mentor. It's fabulous, it's brilliant. I can't think of the words but it's brilliant." (DD10)

"They are absolutely key to this thing working. Their friendliness, their encouragement, they keep in contact. Just the encouragement and their attitude is absolutely brilliant." (DD11 – family member)

The project staff were friendly and personable and provided a high level of communication to the diarists, offering information and updates:

"They're always supporting. I follow them on Twitter, and they follow me on Twitter. And they email me all the time, asking if there's anything I need, anything they want to improve." (DD12)

"And the other amazing thing is that because Laurence has been so patient and understanding and has built up a good relationship." (DD13 – family member)

The team were always on hand to answer questions, or help to solve any problems and showed genuine interest and concern for the diarists and their partners:

“One of the benefits too is that Laurence will phone us up or one of the team members will phone us up and say [name] you haven’t been blogging now are you okay, you haven’t been chatting, is there anything we can do for you.” (DD7)

The ethos of the team to encourage and support is key to the success of the project. One diarist explained that they provide the right amount of support to ensure that diarists feel supported and not pressurised:

“They would phone up and say are you alright, we’re not pressurising you to do it but is there anything we can do to help you. So I didn’t feel used. I felt it was up to you, you could or you couldn’t but we are concerned about you as a person and I like that.” (DD7)

Indeed, some diarists liked the fact that there was no one on the end of the recording device who might criticise what they were saying or try to make them rush the process. They valued being able to speak without have judgement put upon them and being able to contribute at their own pace.

Overall, the team were praised for their ability to allow the project to evolve and adapt and be flexible for the diarists:

“So they didn’t come with this ‘this is the way it’s going to be and its’ rigid and it’s stuck in a box and we’re not moving outside the box’. I think it became bigger because of that and I think that was one of the team’s strengths.” (DD7)

Moreover, using trained journalists to run the project was seen as a key factor of success:

“They’re there, they listen and they promote what you’re trying to put forward and they put it together with their expertise because they are journalists, they can put their own spin on it so they know how it can be accepted by the general public. That’s one of their big strengths really, the fact that they have been in journalism they know how to get the message across into the right place at the right time.”

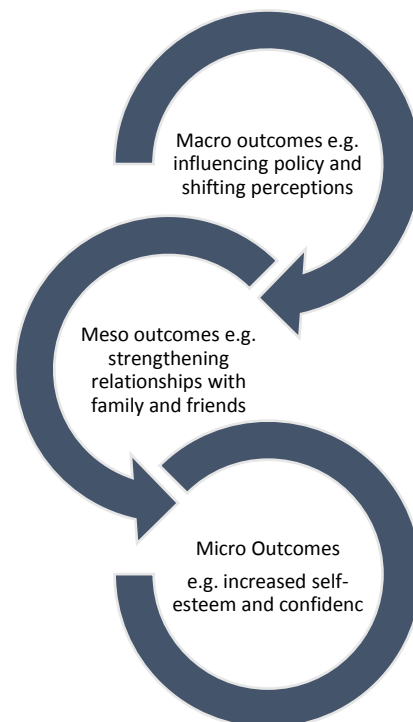
The quote below succinctly captures the overall opinion people had about the project staff and the support provided:

“I think that the team leading are very personable and very approachable and they are very understanding, and they are very honest. And I think that their knowledge of dementia has significantly increased. And they are not too proud to express that. And I think that endears them to me and to others in a sense that you feel as though there is a good professional friendship being built over the course of the project. And I know from talking to other Forget me not members they speak very highly of the Radar team. And I think that motivates people as well to participate because it is easy to lose the thread when it’s all done remotely, and it’s not person face to face.” (DD9)

Impact and outcomes

The data clearly shows that participation as a diarist has multifactorial impacts, operating at micro, meso and macro levels. Clearly, these are inter-connecting and inter-relating processes, but a summary of how this operates is shown below.

Figure 1. Micro, meso and macro outcomes from Dementia Diaries



Micro outcome (1): providing occupational engagement and personal satisfaction

Nearly all of the diarists and their partners reported that the project provided them with a role and a purpose. Recording diary entries gave them something positive to focus upon and work towards. Knowing that their diary entries were being listened to and helping other people made diarists feel useful and valued:

“There’s a few main points. Again the main one is I quite enjoy the role, role and reporter it gives me something to do. You know if you have got Alzheimer’s you need to keep busy all the time and keep your brain busy.” (DD4)

“And she you know, it gives her not a purpose in life but you know something that’s rewarding and she feels that she is contributing instead of you know forever being helped with things. You know she’s actually helping.” (DD6 – family member)

Importantly, some diarists commented that having a role on the project helped them to maintain their sense of self and identity:

“I mean it helps throughout this thing actually in my case, specifically helped me to sustain an identity.” (DD3)

One family member commented on how the production of diary entries had ‘filled a gap’ in the participants’ life – replacing aspects of life that had been taken away by dementia:

“He lives dementia and he knows a lot about it so it’s like a job for him. It’s doing him really good.” (DD16 – family member)

Overall diarists reported that being involved in the project gave them a great sense of satisfaction and accomplishment and many said that they were proud to be part of the project:

“It gives a platform obviously to people with dementia, to talk about their illness. You know to a wider audience. But also I think it gives a personal sense of satisfaction and accomplishment.” (DD11 – family member)

Micro outcome (2): improved confidence and self-esteem

Bolstering confidence and increasing self-esteem was frequently reported by participants as a result of engaging in Dementia Diaries. Individuals mentioned how presenting at conferences, being featured in press releases and news bulletins had given them renewed self-confidence:

“And it’s given her a sort of, a bit more value in her life you know. She can’t work anymore and she can’t drive anymore and there are lots and lots of things that she’s lost so you know. It’s good for her self-esteem.” (DD15 – family member)

“I mean before I was so quiet I wouldn’t talk to anybody. And now you can’t shut me up. It has given me more confidence for when I do talk to people about Alzheimer’s.” (DD6)

Meso outcome (1): strengthening family relationships

The project provided an opportunity for diarists to share their diary entries with family and friends. It was reported that for some, these entries helped friends and family to further understand the condition and what their loved one is experiencing and thus strengthened relationships:

“There were members of the family that were not very understanding. Oh yes I forget things, oh we all forget things. You know they weren’t at all understanding. They weren’t local, they hadn’t seen us for some time and things got a bit awkward. But

strangely enough when I sent them an email and sent them the link to the diaries and they started listening to them and hearing [name] speak, they've actually come round a lot now. So that's been another benefit really. A very personal benefit. It was almost like they now believe him." (DD13 – family member)

One partner of a diarist expressed that involvement in the project led to her feeling more connected to her partner. She suggested that initially she had felt that she was not included in the process of living with dementia but listening to his diary entries gave her further insight into his condition and how he was feeling:

"I always felt like I was getting pushed away but now I don't, I'm more involved... otherwise I wouldn't know what he's thinking or what's going on sort of thing. [Name] is very passionate about things... "That's the only way I know how he does feel. That's the only way he can communicate with me through that so yeah it's been very beneficial to me because then I know how he is thinking and living with his dementia and stuff." (DD16 – family member)

Meso outcome (2): peer support and social capital

Nearly all of the diarists spoke about gaining peer support through the project. Some described it as a 'virtual network' where they felt connected to the other people who report for Dementia Diaries. Some explained that they felt that other diarists were like friends that they knew well and they enjoyed being connected to other people who understood dementia who they could share their experiences and opinions with:

"I went to a conference last week with people I've never met before and everyone said oh it's lovely to put a face to a name because they had seen my contributions on-line because they're On Our Radar as well so we all got chatting together as though we were old friends because we'd seen each other's posts." (DD1)

"And then we started listening to you know the broader group doing it around the UK. And I've started realising there is such a similarity, obviously because of the disease that's the common denominator, the common factor. But besides that there's just such a commonality and a community." (DD11 – family member)

"This was about peer support. Just how important it is to be with people who understand what it's like living with this condition. And that is so valuable." (DD5)

Macro outcome (1): challenging stigma and stereotyping

A key theme to emerge from participants was the sense that Dementia Diaries enables individuals to have a 'voice'. The project provides a platform for people with dementia to raise their views and make their opinions heard. The importance of 'real' voices of 'real' people experiencing dementia was critical, potentially adding greater credibility than professional viewpoints:

"It's not coming from doctors or medical people or council workers, it's coming from us, from the heart, people living with dementia so I think it's a pretty unique way of doing things." (DD4)

"What's really good is that you can hear the emotion in people's voices, it's very profound and I never realised it. I was listening to something and sometimes it wasn't what was being said, the words, it was the emotion behind it and you could almost visualise and touch and taste it. That has a big impact." (DD7)

Diarists perceived that through having a voice and a platform meant that they were better able to challenge preconceived notions of dementia. Diarists commented that the information in their entries can help to reduce the stigma attached to the condition. Diarists explained that a lot of people have common misconceptions around dementia, one of the most common being that it is a condition that only older people experience. They described how people can have predetermined ideas about people with dementia, many of which are unfounded:

"Just because you have dementia doesn't mean you have to shut yourself away and sit in the corner and you can still live an active life. That's why Dementia Diaries that's why it appeals, it's an opportunity to show people that people are still able to function to a great degree and although they're living with a diagnosis we can still focus on the things you can do rather than the things you can't." (DD8)

Macro outcome (2): impact on policy and practice

Diarists anticipated that the project would influence policy and change the way local authorities, the NHS and other vital services manage and care for people with dementia. They stated that the project has enabled them to educate professionals and enabled them to share their views and ideas about dementia and the care that should be provided:

"I think the insight that we have given professionals, not just in the UK but worldwide. And I was at Slovenia at the Alzheimer's conference last year, and I was talking about Dementia Diaries, and again lots of people... Twitter went mad. And you know the number of people following Dementia Diaries from that was huge." (DD5)

Macro outcome (3): digital literacy and connection

One diarist commented that the project is a good way for people to become more digitally literate. The opportunity to contribute to discussions, debates and to influence the agenda from home using the internet allowed people to contribute in new ways. One diarists explained that even when she is not able to go out and physically campaign she can still be an 'active dementia campaigner' from her own home through the dementia diaries project:

"Some dementia people can't use computers. I can't use one, and that's why I'm championing Dementia Diaries because it's a way out for me to speak." (DD2)

"It's so powerful to know something that you are doing, people are going to listen to you. It's so powerful for people with dementia that feel they're lesser people that nobody wants to listen to them, especially the professionals. It's very therapeutic." (DD7)

Moving forward

The participants shared their views on how the Dementia Diaries programme could be improved and developed further in the future. These issues have been summarised in Table 2.

Table 2. Participants' views on future improvements and developments for Dementia Diaries

Issue	Comment	Illustrative quotation(s)
Expanding the concept further	If the project is to develop in the future diarists would like to see the project receive further funding so training can be delivered to more people living with dementia. It was highlighted that it is important to keep introducing new diarists to the project so that the project can grow and expand.	<p>"What I've love to see is Dementia Diaries everywhere in every country, city, village and town." (DD12)</p> <p>"I just hope it goes all over the UK and they can get the funding to carry on everywhere else. Then a lot more people would be able to appreciate all the nuances of the disease." (DD4)</p>
Opportunities for networking	Some expressed that they would like an event where they could meet all of the diarists face-to-face. It was suggested that one event could be held in the north and one in the south. While more face-to-face contact would be desirable, it was conceded that this is not always possible due to funding issues and diarists living in different localities across the UK. It was suggested that web-based video meetings/conferences could be a good way to overcome these issues.	<p>"It might be a good idea for people who use the dementia Diaries to get together and perhaps have a conference. I don't know, but it certainly, I think it would be beneficial because the whole group is all spread all over the country so we could get some ideas of how their dementia is and how their care is cos it varies from different places." (DD2)</p> <p>"I think it would be good if we could have more face-to-face but that's not always feasible. I don't know if there's another way around that but it's not always feasible but there's Zoom and webinars so it wouldn't be that expensive you could set it up that way, where people could talk about their challenges and see faces." (DD7)</p>
Buddying system	One diarist proposed that it would be useful to introduce people to a dementia buddy so that they had friend they could call and ask questions should they need to.	<p>"Maybe it would be good to have a buddy I don't know I've just thought about that. Someone who you could phone up. I would consider [name] my dementia diary buddy where I would share challenges and chat to her about it because she is great and she will just say I'll just call Laurence, whereas my personality is Laurence is busy and I won't bother him and I'll find somebody else to fix it. Whereas [name] goes straight to the source and sorts things out." (DD7)</p>
Opportunities for family members to produce audio content	Some thought that it would be useful to provide a recording device for carers and family members to enable them to share ideas and experiences of caring for someone living with dementia.	<p>"I'd love to see one thing ...carers you know, families carers are the only ones who can tell you what it's like to care for a person with dementia because it's different for every person caring for one another...I think it would be a fantastic idea to let carers have one for their say as well." (DD12)</p>

6. Media analysis and impact

The first part of this section provides a narrative of the media impact created by Dementia Diaries, highlighting the reach, scope and response to the articles that have been produced using the voices of participants. The second part of the section goes further to analyse social media and on-line responses to Dementia Diaries based articles and a randomly chosen sample of comparator articles.

Scope and impact

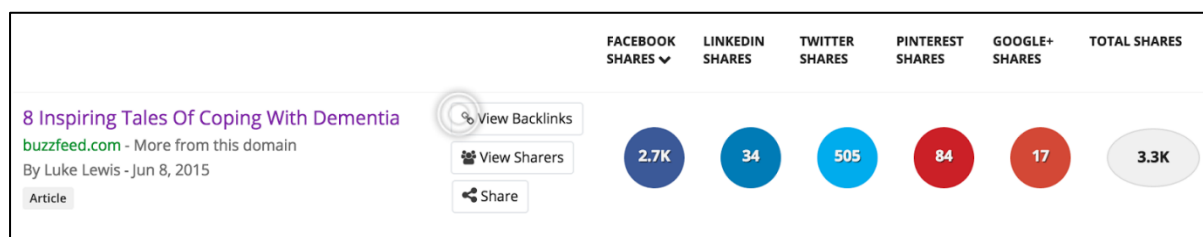
The Dementia Diaries team approach media outlets having worked on a specific story with Dementia Diaries participants over time. The Dementia Diaries team, have an in-depth knowledge of the media landscape and remain vigilant of appropriate media hooks which potentially improves their success in placing media in specific outlets at any given time.

The following are illustrative case studies of the diverse media coverage and scope. While these cases are not exhaustive, they provide an overview of activity.

Buzzfeed (1): 8 Inspiring Tales of Coping with Dementia

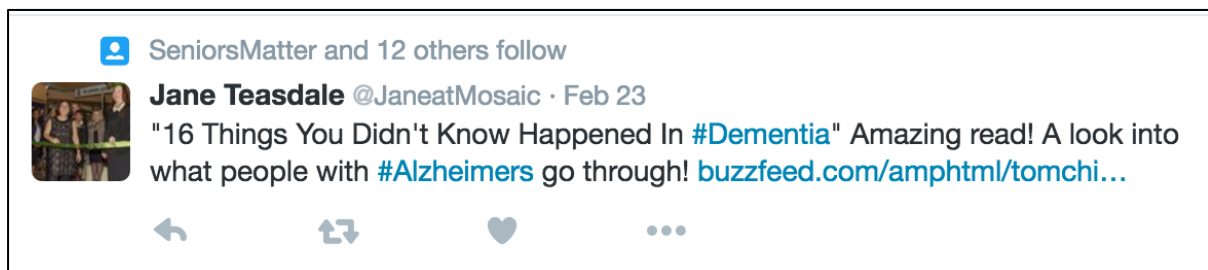
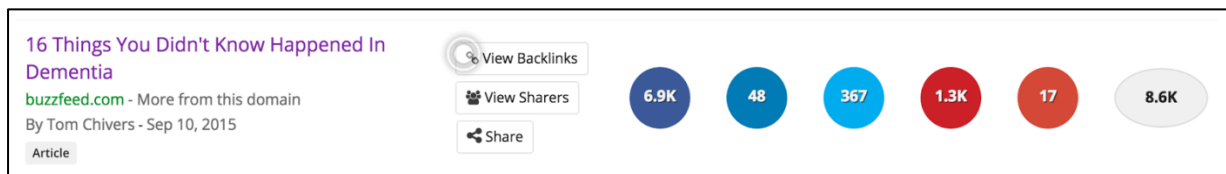
Buzzfeed have a youthful audience (50% are 18-34 years old) and the intention with this article was to bring a new viewpoint to this demographic. Multiple Dementia Diaries reports have emphasised the importance of the message that you can live well with dementia. However, imagery around dementia in the media traditionally leans towards stereotypes concerning, for example, older people, withered hands, confusion and disorientation. Using the voice of Dementia Diarists, the piece wanted to challenge these stereotypical views. A range of interesting stories were selected which were considered to be suitable for a buzzfeed feature article.

A professional illustrator was commissioned to provide powerful artwork for the piece, which in the immediate hours after publication was viewed over 25,000 times. In keeping with the audience's reputation as 'digital multipliers', it has subsequently been shared widely on social media (as seen below).



Buzzfeed (2): 16 things you didn't know about dementia

Following on from the success of the first buzzfeed article, the second article '16 things you didn't know about dementia', was completely in the words of Dementia Diarists. The premise of the piece was that dementia is extremely misunderstood and that preconceived notions should be challenged. The social media impact was very strong, as illustrated by the data on social media 'shares' and on comments and responses by readers.



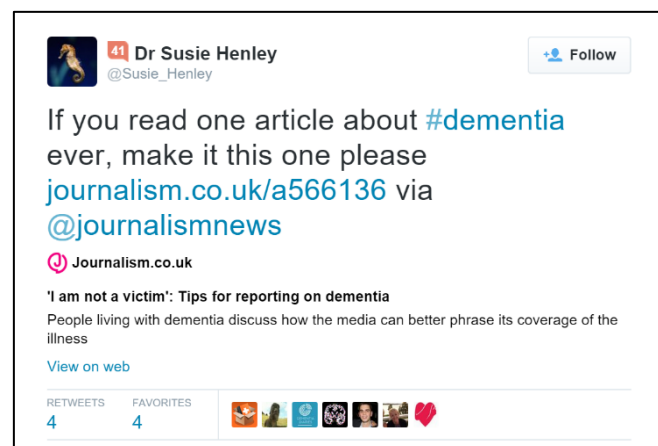
Newspapers – The Telegraph and The Mirror

Both The Telegraph and The Mirror have a track-record in reporting dementia stories, but often using language that is negative in tone. The pieces in The Telegraph ('Dealing with dementia: those living with condition outline 'dos and don'ts' for friends and family') and The Mirror ('How do you know you have got dementia? A group of people share their experiences of diagnosis') were specifically designed to use more positive language using the voice of diarists. Feedback from professionals in the dementia field and those diarists participating in the article were extremely positive. One professional, for instance, stated:

"Just to add my compliments for a first class article, with great balance and the lived experience really shining through unmediated. Well done all - a great triumph!"

Journalism.co.uk

Journalism.co.uk stands alone as a key influencer and educator in the media sector. The article written for the website ('I am not a victim': tips for reporting on dementia') focussed on providing top tips for reporting on dementia, explaining why certain terms can be misleading or upsetting. The explicit focus of the article was to target media professionals: editors, producers and journalists directly. Data shows that the journalism.co.uk article was pushed to more than 700,000 people (including the health editors of the Express, Mail, Guardian and The Times) via relevant social media accounts and was read on average for more than 4 minutes, in contrast to a typical web page which is viewed for less than 15 seconds. Social media reaction to the article was positive, illustrated by several twitter posts:



Smashing magazine

During a website re-design for dementiadiaries.org, the Dementia Diaries team documented their process to improving the web experience for people with dementia. The piece ('Designing a dementia friendly website') was reported in Smashing magazine, which is the

largest online community for developers and designers. For a group of people living with dementia to be directly informing hundreds of thousands of web designers and developers on how to do their jobs is a significant 'leap' across the digital divide. The page was viewed 800,000 times and social media interest was high on all platforms, including Facebook, Twitter, Google +1, Pinterest and LinkedIn.



The piece reached key influencers and audiences; for example, Microsoft's design team and strategists (see below) and feedback from the Scottish government's digital team. Moreover, Microsoft not only shared the article, but highlighted that a key lesson for their own organisation was the need to include people living with dementia when making decisions about design.



Unique, Dementia Diarist led content was broadcast on SKY News TV and online in 3 spaces. Participants involved in the broadcast reacted very positively to the news story:

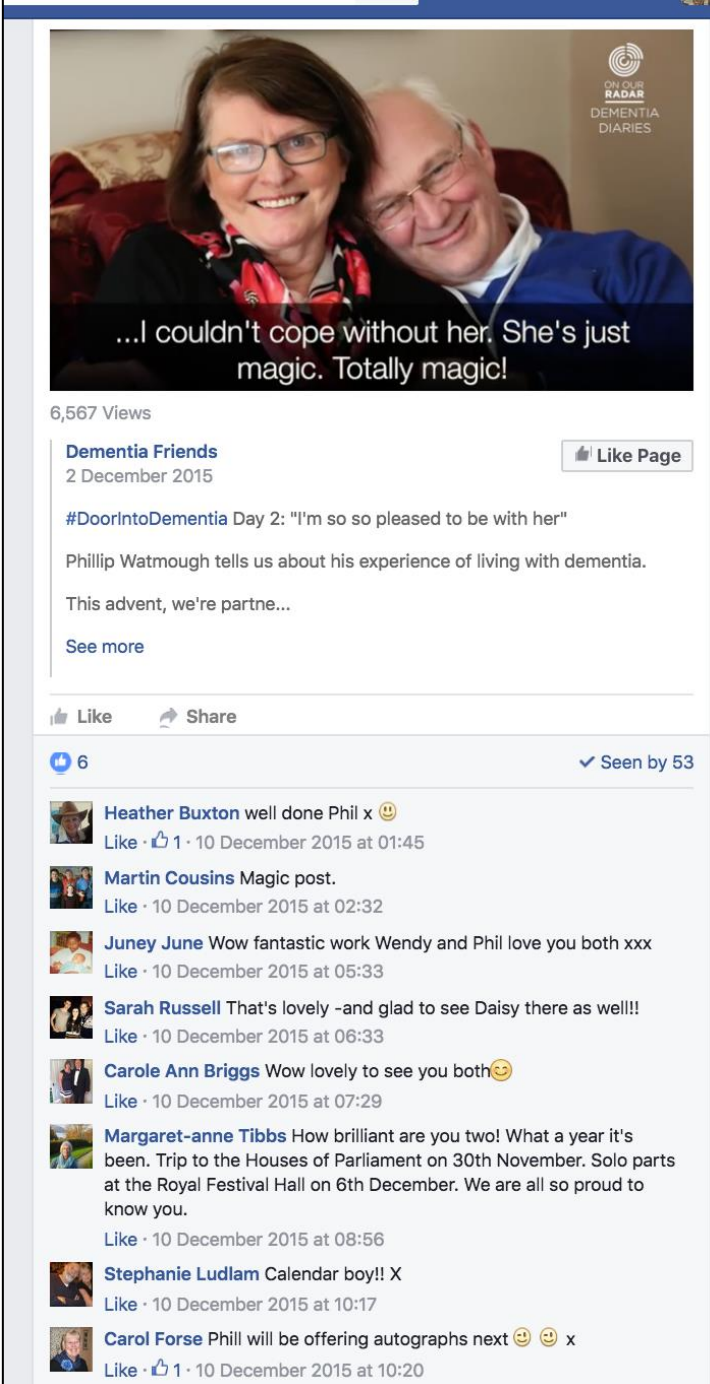
“Wow! First time on the telly for me. My husband was delighted with the news report. He couldn't understand how it happened but thoroughly enjoyed seeing it. I recorded it so we can bore our friends and family to tears for weeks and weeks!!”



Social media campaigns

The Dementia Diaries team have orchestrated a number of social media campaigns, including the Comic Relief Twitter takeover using the hashtag #DementiaDiaries and a further Christmas campaign using the hashtag #doorintodementia.

The Comic Relief Twitter takeover had over 1,500 twitter users join the online conversation. The hashtag trended in the UK, receiving more than 25 million timeline deliveries and reaching an estimated 3.9 million users. The Christmas campaign 'Door into Dementia' had more than 160,000 people watch the Dementia Diarists post videos which were released on the Dementia Friends' Facebook and Twitter pages. Social media reaction to the campaign was also extremely positive:



6,567 Views

Dementia Friends
2 December 2015

[Like Page](#)

#DoorIntoDementia Day 2: "I'm so so pleased to be with her"

Phillip Watmough tells us about his experience of living with dementia.

This advent, we're partne...

[See more](#)

Like Share

6 Seen by 53

Heather Buxton well done Phil x 😊
Like · 1 · 10 December 2015 at 01:45

Martin Cousins Magic post.
Like · 10 December 2015 at 02:32

Juney June Wow fantastic work Wendy and Phil love you both xxx
Like · 10 December 2015 at 05:33

Sarah Russell That's lovely -and glad to see Daisy there as well!!!
Like · 10 December 2015 at 06:33

Carole Ann Briggs Wow lovely to see you both 😊
Like · 10 December 2015 at 07:29

Margaret-anne Tibbs How brilliant are you two! What a year it's been. Trip to the Houses of Parliament on 30th November. Solo parts at the Royal Festival Hall on 6th December. We are all so proud to know you.
Like · 10 December 2015 at 08:56

Stephanie Ludlam Calendar boy!! X
Like · 10 December 2015 at 10:17

Carol Forse Phill will be offering autographs next 😊 😊 x
Like · 1 · 10 December 2015 at 10:20

Other significant contributions

There are other indicators which demonstrate the reach and impact of Dementia Diaries.

- Having followed the Dementia Diaries project, De Correspondent (a well-respected media outlet in Holland) will run a six month special feature based on the Dementia Diaries model. The Dementia Diaries team have shared all of their resources (training, contacts, consent forms etc.) and De Correspondent are currently setting up the project to begin at the end of the summer 2016, giving recording devices out to 30-40 participants with the intention to provide focused media pieces. They will run

a special series of feature articles as well as a podcast series (De Correspondent have the most followed podcast in the Netherlands).

- DEEP have committed to continue the diaries project for a further 6 months using their own funds and are applying for funding to roll out the project for a further 3 years.
- The Dementia Diaries team presented to the Alzheimer's Society digital team about how they could replicate the approach. The Dementia Diaries team are providing informal support to the Alzheimer's Society and it is expected that content generated by the project will be used when they re-launch their website early next year.
- The Dementia Diaries team were requested to produce a series of videos for the Department of Health to be shown at a major conference this autumn. These will be viewed by the Secretary of State for Health as well as the Heads of the UK Clinical Commissioning Groups. More importantly, the Department of Health have written Dementia Diaries into their strategy for the Dementia 2020 Citizens' Panel, where it will be used as one of several methods to gain insights from a diverse range of people living with the condition.

The impact of Dementia Diaries media content against comparator stories

A small scale review of social media and on-line responses to Dementia Diaries based articles were compared against a randomly chosen sample of comparator articles. This was a methodology for assessing article impact, which we piloted within this evaluation.

Randomly chosen articles were picked on the basis of being on the topic of dementia, posted on the same form of social media in close time proximity to the Dementia Diaries article and which contained comments from the intended audience. Some Dementia Diaries articles and potential comparator sites had to be excluded because they did not permit comments to be posted (many of the newspapers) or did not have any comments posted for analysis (e.g. Comic Relief film on YouTube). One included the direct voice of a person with dementia and two did not, to allow for comparison of inclusion of the direct voice and of the methods used specifically within the Dementia Diaries project to package and present the voices of diarists to a public audience. The articles that were analysed were three articles written by the Dementia Diaries team:

1. BuzzFeed post '16 Things you didn't know about dementia'
2. Journalism.co.uk article 'I am not a victim: Tips for reporting on dementia'
3. Smashing Magazine article 'How to design a dementia friendly website'

And three comparison articles:

1. The Mental Health Foundation article 'I was admitted to a psychiatric unit'

2. Joseph Rowntree 'Dementia Without Walls'
3. The Alzheimer's Society '5 things you should know about dementia'

Author and title	Place published and content analysed	Date published	Description
Dementia Diaries '16 Things you didn't know happened in dementia'	https://www.buzzfeed.com/tomchivers/things-you-didnt-know-happened-in-dementia?utm_term=.eyVOvYRoO#.yhBGe7P3G – analysis of 28 comments	10 September 2015	Article explaining that dementia involves much more than memory loss and confusion. Includes personal accounts and experiences from people living with dementia
Dementia Diaries 'I am not a victim: Tips for reporting on dementia'	https://www.journalism.co.uk/news/i-am-not-a-victim-tips-for-reporting-on-dementia-/s2/a566136/ - analysis of 4 Facebook page comments and 15 Twitter comments	18 August 2015	People living with dementia discuss how the media can better phrase its coverage of the illness.
Dementia Diaries 'How to design a dementia friendly website'	https://www.smashingmagazine.com/2016/05/designing-a-dementia-friendly-website/ – analysis of 19 comments	17 May 2016	Key features of a dementia-friendly website: making websites more accessible to people living with dementia. Designers suggest key lessons to support people who are excluded from the benefits that the internet has to offer.
The Mental Health Foundation 'I was admitted to a psychiatric unit'	Mental health Foundation Facebook page -- 50 comments	19 May 2015	Brief account from Carol who was admitted to a psychiatric unit and treated for psychosis and hallucinations before being correctly diagnosed with dementia. Short statement using Carol's own words with not additional context or

			background information.
Joseph Rowntree 'Dementia Without Walls'	Original link to article has been removed from the Joseph Rowntree website. Analysis on 14 Facebook page comments.	24 Feb 2015	Overview of the Dementia without Walls project. While the project engaged people with dementia the article analysed did not include the direct voice of people with dementia.
The Alzheimer's Society '5 things you should know about dementia'	Alzheimer's Society Facebook page – 40 comments	28 Dec 2015	Link to Alzheimer's Society booklet of the same name aimed at dispelling myths about dementia. Did not include the direct voice of people with dementia.

While the results must be treated with caution, this analysis did suggest the direct use of the voice of the person with dementia, whether via Dementia Diaries or via one of the comparator articles, generally produced more empathic and supportive comments than stories produced, for example, by a charity that did not include the direct voice of individuals.

Support, compassion, empathy and commonality of experience

Personal accounts of experiences of living with dementia or accessing health services commonly invoked personal messages of support and empathy for the person involved. This might also be critical of the service or experience a person received, but was underpinned with compassion and empathy for the person and their situation:

"Glad they continued to search for reason why. Most don't bother." [Comparison article: The Mental Health Foundation article 'I was admitted to a psychiatric unit'] (Mental Health Foundation Facebook post)

"An illness is an illness and people deserve respect and to be treated with dignity and compassion." [Comparison article: The Mental Health Foundation article 'I was admitted to a psychiatric unit'] (Mental Health Foundation Facebook post)

Those commenting on social media also shared their own similar experiences either as a person living with dementia or as a caregiver, creating a sense of commonality and connectedness with the person/people featuring in the article:

“I got bullied, relentlessly by staff at 3 mental health hospitals. I also got bullied by patients, and staff responded with oh, she’s not very well...they obviously didn’t give a damn that I wasn’t well.” [Comparison article: The Mental Health Foundation article ‘I was admitted to a psychiatric unit’] (Mental Health Foundation Facebook post)

“I see these things I could scream with pain thinking of all my beautiful mother is going through so many things happening to her she can change 3 or four times in a day.” [Dementia diaries article: The Buzzfeed post ‘16 Things you didn’t know about dementia’] (Buzzfeed post)

“This article is good, worth a read, as a younger person with a recent diagnosis of FTD I am already withdrawing from accessing services because of many reactions, interactions, and language used by those services.” [Dementia diaries article: Journalism.co.uk article ‘I am not a victim: Tips for reporting on dementia’] (Facebook post)

Experiences of being a carer

On-line articles encouraged people to share their personal experiences of caring for someone with dementia. Largely the articles that contained the personal experiences of a person with dementia, whilst discussing the challenges of a caregiving role, also contextualised these within an appreciation of the benefits that their caregiving offered to their loved one. They also provided carers with the opportunity to share their experiences and tips and thus to act as expert advisors to others about things that might help:

“My sister has been diagnosed with early onset dementia due to trauma. Coupled with two strokes. It is hard to know what to do. I have asked her if she would rather I not finish her sentences for her and she told me to look in her eyes and see if there is any one there and then use my judgement” [Dementia diaries article: The Buzzfeed post ‘16 Things you didn’t know about dementia’] (Buzzfeed post)

“Please reach out to the Alzheimer’s Association. There are resources that you may not be aware of. Learning about dementia will be a great help for you and your sister. It is also a good idea to talk about what she wants when she can no longer communicate. Put everything in writing, including her end of life decision. It will take away the burden from the family. Use music around her, her favourite music.”

[Dementia diaries article: The Buzzfeed post '16 Things you didn't know about dementia'] (Buzzfeed post)

In addition the posts offered carers with the opportunity to share difficult experiences and in some cases others responded with advice and support, creating an impromptu peer support opportunity:

"My mother developed pneumonia at home. The doctor insisted she go to hospital. She didn't want to go. Should I have kept her at home? She may have died a few days later. Instead she was in hospital for three weeks, prodded and poked, drips, injections, scans and died, alone, three weeks later in the hospital. She was 95. Difficult decisions."

Response:

"[Name] you loved your mother and admitted her because the doctor insisted. Please know that everything happened as it should have & don't beat yourself up for the decisions that were made. God has a plan for each of us.... including your mom. None of us will understand some of the things that happen in our lives but someday it will all make perfect sense. She is free of pain now and in the presence of God. God loves you and wants you to live a happy life. Don't regret decisions made out of love. God bless you :)"

[Dementia diaries article: The Buzzfeed post '16 Things you didn't know about dementia'] (Buzzfeed post)

Some of those in caregiving roles also discussed how helpful articles using the direct voice of people living with dementia had been in helping them to share information about dementia with others through providing a succinct valuable resource and reminding them were not alone struggling to care for someone with this condition.

"So glad this came up on my news feed. I have been delving into learning everything I can about dementia and trying to explain my mom's issues to my family has been challenging. I felt this was short and helpful to share" [Dementia diaries article: The Buzzfeed post '16 Things you didn't know about dementia'] (Buzzfeed post)

"This article has been so helpful. I care for my dad who has vascular dementia and all of these symptoms (except the hearing). Reading other peoples experiences who suffer with the same things makes it so much easier to care for him. As (names other page user) from above said it made it easier for me to separate out the illness from the person I knew as dad knowing that the things he talks about are common to others an

therefore the illness and not just him, being difficult" [Dementia diaries article: The Buzzfeed post '16 Things you didn't know about dementia'] (Buzzfeed post)

Challenging the article

Our analysis suggested that articles not directly involving the experiences of those living with dementia frequently generated strong, negative, opposing perspectives some of which challenged the views expressed in the articles, particularly those that presented people with dementia as still capable of many things:

"It's good that AS is promoting facts and honest information but overdoing the 'things go on normally' and not acknowledging the fact that for everyone involved there is a terrible loss through these changes. Please add the fact of grief, loss and mourning that goes alongside the living with dementia information." [Comparison article: The Alzheimer's Society '5 things you should know about dementia'] (Alzheimer's Society post)

"To say that "dementia doesn't change who they are" is disingenuous. This dreadful disease absolutely changes who the person is, often into someone who is completely unrecognisable. It may happen over a number of years but it happens. I know. My sister has Picks at 55 diagnosed at 48 and there is no trace of the bright, beautiful and loving person she once was." [Comparison article: The Alzheimer's Society '5 things you should know about dementia'] (Alzheimer's Society post)

Some of those making comments challenged the expertise and knowledge of those who had written the document.

"No 4 and 5 are absolute rubbish. Obviously the people writing this do not have first hand experience of living with a person who has Dementia." [Comparison article: The Alzheimer's Society '5 things you should know about dementia'] (Alzheimer's Society post)

Some also offered advice to others which was incorrect, inaccurate or had limited evidence base:

"many people with dementia continue to drive'....are you serious? Once diagnosed with dementia it is advised you hand in your driver's licence. Telling people this is very irresponsible, especially for a charity." [Comparison article: The Alzheimer's Society '5 things you should know about dementia'] (Alzheimer's Society post)

While utilising the direct voice of a person with dementia, the very brief Facebook post from the Mental Health Foundation, also produced some negative responses challenging the content. These related to a lack of clarity in the post about what the argument being made

was. Our interpretation was that the post intended to highlight how there is a lack of awareness about dementia and it can often be mistaken for other illnesses or misdiagnosed, given the story was posted under the banner of 'dementia awareness week'. However, some of those adding comments felt the post was in fact making a point about dementia being a medical and not a mental health condition and were critical of this view.

"A medical issue, rather than a mental health issue"?! Really sad to see this worrying stance that only adds to stigma from Mental Health Foundation of all places!!"

[Comparison article: The Mental Health Foundation article 'I was admitted to a psychiatric unit'] (Mental Health Foundation Facebook post)

"when did dementia become a medical issue? or more of a medical issue than bipolar or schizophrenia?" [Comparison article: The Mental Health Foundation article 'I was admitted to a psychiatric unit'] (Mental Health Foundation Facebook post)

"Dementia is a mental health problem ! As it is medical" [Comparison article: The Mental Health Foundation article 'I was admitted to a psychiatric unit'] (Mental Health Foundation Facebook post)

Therefore, there appeared to be something important about the way in which the voices of people with dementia are presented and packaged for a public audience that made a difference to the reactions received. The Dementia Diaries articles appeared to do this more successfully than the comparator article.

Negative language

Articles on dementia that did not include the direct voices and experiences of people with dementia produced responses that while were still supportive of the content and sentiment behind it, were more negative in their perspective of people with the condition and life as a carer.

"Well done Rowntree!! And thank you, my mother suffered with this dreaded disease, in my opinions." [Comparison article: Joseph Rowntree 'Dementia Without Walls'] (Joseph Rowntree post)

"My dad suffered this awful illness. Sadly we lost him 18 months of heartache, watching is memory and mobility slowly fade away...soul destroying." [Comparison article: Joseph Rowntree 'Dementia Without Walls'] (Joseph Rowntree post)

"I know all about dementia - you get it, you die, just like my lovely husband did after suffering for 8 years!" [Comparison article: The Alzheimer's Society '5 things you should know about dementia'] (Alzheimer's Society post)

Not all comments to posts without direct involvement of people with dementia were negative, and comments did demonstrate an appreciation for any useful content and information about how to care for someone with dementia, but these were less frequent:

"Very informative, thank you. My Mom diagnosed with Vascular Dementia, I read all I can about this horrid disease. The more info I have the better I can communicate with her. Using simple words, sending cards with a visual picture (easier to comprehend). Phone calls are a bit tricky. You just have to think outside the box sometimes. Again thank you for all the info." [Comparison article: The Alzheimer's Society '5 things you should know about dementia'] (Alzheimer's Society post)

Summary

While we have to remain tentative in what conclusions we can draw from this analysis due to the limitations of the design and data available, the comments do suggest that people find on-line content about living with dementia useful and informative. Where people with dementia are directly involved in generating the content and it is presented in their words responses appear to generate a greater sense of positive connectedness and empathy. People appear less likely to challenge the accuracy of content that comes from the experiences of people living with dementia and may be able to better relate personally to it.

7. Conclusions and recommendations

This evaluation has demonstrated the impact and contribution Dementia Diaries has made to individual diarists and in attempts to influence media coverage and key services which affect the lives of people with dementia. As evaluators, and based on the evidence gathered, we are confident in our conclusion that the project has been successful and has met its intended goals, especially in relation to making a difference to the lives of the diarists involved. The original theory of change developed collaboratively between the evaluation team and the Dementia Diaries team provided a framework for the evaluation and has enabled an assessment of the value of Dementia Diaries and an indication of the strength of the evidence gathered through this research (see appendix 1 for further details).

For a project in its relative infancy the range of media outputs has been impressive, coupled with the traction that has been made on social media. As has been reported, the Dementia Diary project reach has covered a large demographic using outlets such as buzzfeed, Sky news and other platforms. This evaluation has used a range of evidence sources and approaches and has demonstrated strong evidence that Dementia Diaries is having multifactorial impacts, operating at micro, meso and macro levels. Individuals involved in Dementia Diaries reported very positive health and social effects as a result of their participation, including bolstering confidence and increasing self-esteem. There is also strong evidence that shows the benefit of Dementia Diaries in fostering a sense of peer support, collective ownership and sense of sharing experience. However, positive effects reached beyond individual diarists and there is some evidence to demonstrate that family relationships had been improved and strengthened as a consequence of Dementia Diaries through better understanding between individuals. The mechanisms by which these personal outcomes are achieved are enhanced significantly by the Dementia Diaries team who support and mentor diarists and their families with care compassion and huge professionalism. Any replication of the model must integrate this supportive infrastructure.

From a broader perspective in relation to influencing media coverage and challenging preconceived notions of dementia, there is a body of evidence which shows the impact that Dementia Diaries has had. Although the scale and scope of the evaluation means that findings should be treated with caution, diarists perceived that through having a voice and a platform to share their experiences, predetermined ideas of dementia in society had been

contested. Indeed, the analysis of media coverage and social media responses does show that where people with dementia are directly involved in generating the content and it is presented in their words responses appear to generate a greater sense of positive connectedness and empathy.

There was weaker evidence that Dementia Diaries had influenced policy and changed the way local authorities, the NHS and other vital services manage and care for people with dementia. That said, there were indications that the project had enabled diarists to educate professionals and provided an opportunity to share their views and ideas about dementia and the care that should be provided. Further longitudinal work will be necessary to determine this impact fully.

In terms of the future progression of Dementia Diaries, there is little doubt that further funding would likely continue the outcomes demonstrated here. There are, nevertheless, issues for consideration that are listed below that Dementia Diaries may wish to consider in order to develop and improve service delivery. The transferability of the Dementia Diaries concept to other areas is a future prospect that should be considered – there is no evidence to suggest the programme attributes or benefits are peculiar to dementia, which opens the possibility of transferring this model to other fields.

In terms of issues for future considerations:

- Opportunities for family members to produce audio content should be considered alongside those directly experiencing Dementia.
- The possibility of diarists networking in-person as well as virtually should be explored given the positive impact that peer support and sharing common experiences can have on individuals and families.
- The infrastructure that the Dementia Diaries team have created which supports diarists and their families is recognised as a significant factor in the project's success. If the project expands further, the team must be mindful to ensure that the high-level support remains.
- Media content should continue to be diverse in order to target a wide demographic.

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Appendix 1. Assessing the strength of evidence gathered

Area of Dementia Diaries activity	Strength of evidence	Enhancing the evidence base
Engaging and securing opt-in of people living with dementia	<p>Evidence level: Strong</p> <p><i>The evaluation data has shown the number of participating diarists and moreover the number of audio blogs submitted. Qualitative data shows that diarists are enthusiastic and engaged in the process.</i></p>	Continuing to gather monitoring data on the numbers of diarists participating in the project is essential to track reach and engagement.
Training participants	<p>Evidence level: Moderate</p> <p><i>The training process to enable diarists to understand the technology and purpose of the audio blogs they would create was received, almost universally, positively.</i></p>	This evaluation was able to gather qualitative insight into the training experiences of diarists. Gathering quantitative data from a sample of the participants engaged in the training sessions would add increased value to the qualitative information.
Connectivity, capacity and confidence	<p>Evidence level: Strong</p> <p><i>There was strong evidence that diarists and their families feel supported and enabled to complete an audio diary. Relationships developed between participants and the Dementia Diaries team was considered a key mechanism to the project's success.</i></p>	<p>Being able to capture participants' open and honest views on the support they have received from the Dementia Diaries team can potentially be difficult for the team to collect themselves.</p> <p>Enabling diarists to speak confidentially to external and independent parties about their views on the project is essential.</p>

<p>Participants' voice amplification</p>	<p>Evidence level: Strong</p> <p><i>Routine monitoring data shows that almost 2000 audio diaries have been submitted and 526 have been published on the dementia diaries website. Data shows that much of this material has been utilised by media organisations. Qualitative data shows the importance of participants' voice amplification for their own sense of well-being. Nearly all of the diarists and their partners reported that the project provided them with a role and a purpose. Recording diary entries gave them something positive to focus upon and work towards.</i></p>	<p>The Dementia Diaries team already have a systematic process for</p>
<p>Improved public understanding and reconfiguring perceptions of dementia</p>	<p>Evidence level: Moderate</p> <p><i>Diarists perceived that predetermined ideas of dementia in society had been contested through the project. The analysis of media coverage and social media responses also demonstrates that where people with dementia are directly involved in generating the content and it is presented in their words, responses appear to generate a greater sense of positive connectedness and empathy.</i></p>	<p>Given the scale and scope of the evaluation, findings must be taken cautiously in relation to the design employed. Future research and evaluation efforts should track the impact of media outputs and develop measures for assessing public perceptions of dementia and how these may be re-cast as a result of Dementia Diaries.</p>